

Maine Newborn Hearing Program Advisory Board

Senator Inn & Conference Center, Augusta Maine

Date: May 28, 2008

12:00 to 4:00

Members Present: Romy Spitz, Eileen Peterson, Karen Harrison, Karen Hopkins, Karen Perry, Kristen Shorey, Louise Packness

Program Staff: Toni Wall, Betsy Glencross, Amy Peaslee, Pattie Gravel, Jim Dean, Vivian Mikhail.

Interpreters: Mary Jane Grant, Tina Morrison

Guests: Lynn Schardel (Maine Education Center for Deaf & Hard of Hearing), Jennifer Libby (hear ME now!)

Members Absent: Harriet Gray, Carrie Ouellette, Cindy Brown, Annette Bowman, Deb Stroud, Brenda Medlin, Michelle Markie

Moderator: Betsy Glencross

Scribes: Toni Wall, Betsy Glencross, Amy Peaslee

Approval of minutes from: **March 14, 2008, accepted.**

I. Presentation: Karen Hopkins, Lynn Schardel and Vivian Mikhail

"The Double-Edged Sword of Early Hearing Detection and Intervention"

This presentation was originally given at the EHDI (Early Hearing, Detection and Intervention) National Conference in New Orleans, Feb 2008.

II. MNHP Update: Betsy Glencross and Toni Wall

- Toni provided updates on both the HRSA and CDC-EHDI grants. The information provided in the previous meeting's minutes is accurate. Both grants were submitted. We hope to hear about the CDC grant by mid-June and the HRSA grant by mid-July. (BG note: as of June 25th, no word yet from CDC)
- Loss to documentation:
 - Eileen emailed data provide to the Board at the March meeting to (MAA) Maine Academy of Audiologists, and Betsy received immediate response. Many missing reports were received and one practice called to make sure MNHP had all their reports.
 - Jim Dean and Betsy sent letter to all licensed Maine audiologists explaining the reporting mandate and some guidelines for reporting to MNHP.
 - Pattie Gravel is calling PCPs (primary care providers) of those babies who referred on hearing screen and for whom we have no follow-up report in order to clean-up data, getting missing reports, etc.
 - Vivian is calling parents of babies who refer and for whom we have no follow-up reports.
 - We have improved our follow-up rate for 2007 data. It was at 32% in March 2008 and is at 40% as of May 28.
 - 2008 reporting also appears to have improved.

- ECFS: Early Childhood and Family Services and MNHP have developed a form that will allow ECFS to share important Early Intervention data with MNHP. They are finalizing the document on June 4th. Betsy has been and will continue working with ChildLINK to utilize this data for reporting.
- Ballard House is closing. The midwives will no longer be practicing there. Betsy did hear that CMMC is taking over their practice and will contact them about continuing with hearing screens. *(BG note: I have since learned that CMMC is taking over the practice, which was based in Norway, but they are not going to be doing anything at Ballard House. Ballard House is now closed to births and Betsy received the screener back from them.)*

III. Parent Support Update: Vivian Mikhail

- Focusing on calling families of babies that refer and for whom we have no follow-up results or that appear to have not been screened at birth. Many have either incorrect phone numbers or don't answer phones (assuming that perhaps Caller ID is an issue and they don't recognize the number so don't answer) Although it seems that this year seems to be going better than when started in 2007. The biggest challenge to date is just getting the families on the phone.
- Hands and Voices, Maine Chapter: This is part of a National group that provides support for families of children with hearing loss. The National Organization has been around for 15 years and 25 states have chapters. There have been two successful meetings in Portland and Bangor and will be setting up meetings this summer in Rockland and Lewiston with plans to have one or two meetings farther north in the near future. The next step is to set up a Board. The National Organization selects the Board members from the applicants. Strong family members and professional members are needed. Contact Vivian for more information. At the meetings already held, families expressed the need for socialization, connections with other families. Some don't know what they want. A lengthy list of goals/objectives/thoughts was developed from these sessions.

IV. Audiology Consultant Overview/Update: Jim Dean

- Betsy gave a brief overview of the audiology consultant's role which was outlined in a document provided in the meeting packet.
- Jim introduced himself and gave brief background of his professional experiences.
- Working with Betsy on getting the audiology facility questionnaire completed and out to facilities to update our listings.
- Plans to visit audiology facilities starting with Category A sites and will try to visit Category B facilities as time allows. He is offering support and gathering pertinent information for MNHP to help continue the good collaborative relationships we are developing.
- Karen Harrison suggested that Jim make connection with Family Practice Residency Programs and provided Jim with a contact to help facilitate this.
- Jim hopes to be able to provide some presentations/educational opportunities to PCPs.

V. Actions Items from Previous Meeting

- **Subcommittee Updates:**

- **Specialty Provider: Romy Spitz**
 - Just waiting on finding someone to create a searchable database so we can get data gathered and entered. This database will only be self-referred providers, no endorsement from MNHP on the services/providers.
 - Toni reports there is such a database available and that it could be up and running by September. We will want to link it to the MNHP website.

Next Steps: Toni to email Romy
 Responsible Person: Toni Wall
 Time Frame: ASAP

- **Membership: Kristen Shorey & Karen Perry**
 - Two people who qualify for the “parent of a hard of hearing or deaf child” seat are very interested in an appointment but are concerned about what to do about a “résumé.” Betsy clarified that it does not have to be a formal résumé but just a list of qualifications for the position. Betsy will email the requirements for application to Kristen and Karen **(DONE)**
 - Still need to work on getting someone for the “culturally deaf” seat.
 - Betsy reports that Lisa Sockabasin, Director of Minority Health Program for Maine CDC/DHHS was suggested for appointment by Valerie Ricker, Director of Family Health to replace Dick Aronson’s seat as Representative of the Department. Lisa is very interested in being appointed and Betsy is working with her to get her paperwork completed.
- **Educational Materials: Louise Packness**
 - The group has met and worked on some goals and started developing a ‘script’ for birth facilities to use when discussing hearing screening and the associated results with families.
 - They also would like to present educational information to Speech Language Pathologists and the Maine Academy of Audiologists at their respective meetings/conferences.
- **Survey:**
 - Betsy reported that after the last meeting, she learned that a family survey had been developed prior to her hire in 2006 and was going to be used to send out to families. She sought input from Karen and Romy and the survey was already in the process of being sent out to mothers who gave birth in the last six months of 2007. A sample of the survey was included in the meeting packet. Our hope is to get a 10% return rate.
 - Amy Black from the Maine Center for Public Health is working with MNHP on the evaluation of the survey results.
 - We need to have this completed by the end of July 2008.
- **Rules: Deb Stroud & Romy Spitz**

- Nothing has been done on this to date. There are rules that need to be written. This is largely a subcommittee that can ‘meet by email’ and requests were put out for Board members who do not already have a subcommittee assignment to consider serving on this.
- **Legislative Updates: Betsy Glencross**
 - LD2295: The original legislation as well as the amendment was included in the meeting packets. This legislation comes from the Work Group to study Early Childhood Hearing Loss and was put under the MNHP legislation. The bill as amended was signed by the Governor in April. Once this becomes law (mid-July), birth facilities will be required to arrange for a follow-up appointment with an audiologist on all babies who refer on their newborn hearing screen (unless the parents refuse) and they must notify the baby’s PCP of this information. MNHP will be working with the Rules subcommittee and birthing facilities on getting this accomplished.
 - Public Law, Chapter 450 (part A, section 8): Betsy just learned of this legislation that was passed and became law in September 2007. The law requires that MNHP report to Child Development Services all babies who refer on their newborn hearing screen and are either diagnosed with hearing loss or we have no follow-up information. We already report all those for whom we receive a diagnosis of hearing loss but we will need to work out a system for reporting those babies that are those we consider ‘lost to documentation’ after 6 months of age. *(BG note: a copy of this piece of the legislation is included in your meeting minutes mailing.)*

VI. New Agenda Items: none

VII. Networking/Sharing Info:

- Romy reported on the 20th Annual DHHS Deaf/Hard of Hearing/Late Deafened Conference being held at Mackworth Island, Falmouth on June 20th. She will email the information to the entire board. **(DONE)**

VIII. Wrap up, Action Items Summary, Plan for Next Meeting:

- Next meeting is **Wednesday, September 10, 2008** at the Senator. The agenda will be sent out approximately one month in advance.
- The Board requested that Betsy contact Janet Farrell from Massachusetts. Janet is our NCHAM (National Center for Hearing Assessment & Management) support person. We would like her to come and provide the board with information/guidance on working on improving the Early Intervention piece of our program.